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status Report

The Quarterly Newsletter on
Disability Issues in Alberta

THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

AUGUST 2001

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NCR, Royal Bank Unveil Accessible ATM

In July, NCR and the Royal Bank debuted a new ATM designed to make banking a whole lot easier for people with disabilities.

The two companies conducted focus group sessions in Toronto using the accessible ATM. The goal was to further refine user preferences and needs.

"Basically, the accessible ATM is a concept that NCR designed in order to serve banking customers who have a wide range of capabilities—from computer literate to those with physical disabilities," says Sacha De Groot of NCR Canada's Financial Solutions Division. "This ATM is equipped with a second lowered keyboard for wheelchair users, larger navigation buttons for those with motor difficulties and also raised leader lines and icons to serve blind customers."

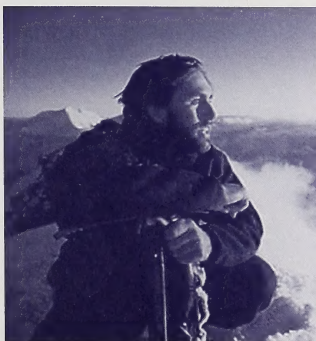
The Royal Bank and NCR have partnered in the past to provide audio lead-through-service for blind users. Both companies routinely meet with third party organizations to understand emerging standards and create solutions that provide easy access to self-service terminals by virtually all members of our society.

People with disabilities have long complained about the inaccessibility of ATM machines currently being used in the banking industry.



The accessible ATM will make it easier to grab some cash.

Blind Climber Summits Everest



Colorado climber Erik Weihenmayer has become the first blind person to scale the world's highest peak.

The feat was accomplished on May 25 after months of preparation and an unusually difficult climb, thanks to severe weather conditions.

"I can't believe it. We're on top, I can't believe it," radioed Weihenmayer to his base camp.

Weihenmayer's team totaled 19 experienced climbers, all of whom reached the summit as well. The final ascent took more than 19 hours.

For Weihenmayer, a 32-year-old adventurer from Englewood, Colorado, the achievement brings him

closer to his goal of climbing the seven highest peaks on each of the seven continents—a feat achieved by fewer than 100 climbers.

Weihenmayer became totally blind at the age 13 due to glaucoma. He hasn't let his disability stop him from becoming a renowned speaker, writer, wrestling coach, acrobatic skydiver, scuba diver, long-distance biker, marathon runner, skier and mountaineer.

Weihenmayer's latest feat is impressive, but he isn't the first person with a disability to scale Everest. That honour was captured in 1998 by fellow American Tom Whittaker, a single-leg amputee.

Last year, Ross Watson of Cochrane, Alberta, made headlines by becoming the first blind person to scale Canada's highest peak, the towering Mount Logan located in Yukon's Kluane National Park.

Consultant Reviews AADL Mandate

Alberta Aids to Daily Living (AADL), the government program charged with providing a wide variety of basic supports to people with disabilities, has completed an in-depth review of its operations. Carried out by an independent consulting firm, the review resulted in 19 recommendations—many of which would see a marked improvement in service for people with disabilities, should they be implemented.

The review began last November. It was deemed necessary in light of the changes occurring throughout the health system.

In 1981, the Alberta government established the program to assist Albertans in maintaining independence in their home or home-like setting, through the provision of basic medical equipment and supplies. AADL, in cooperation with health professionals, approximately 2000 authorizers and about 800 vendors, assist eligible Albertans who have a long term disability or illness

(six months or longer), and individuals who are end-stage palliative. From 1996 to 2000, the number of clients increased by 40 percent, from 50,000 to 70,000. The program's budget rose in the same time period by 30 percent, from \$50 million to \$65 million.

Clearly, there have been significant environmental changes affecting the development and delivery of the AADL program—health system changes, aging population, early discharge from hospital and a marked increase in the complexity of clients remaining in the community. These factors and others led AADL to review its mandate to ensure the program maintained its relevance.

Specific objectives of the review included determining the major factors influencing the future demand for the AADL program, developing specific program principles to guide the AADL program in the future, designing a process to assist AADL in deciding which ben-

efits and products should be eliminated and which should be added to the program, recommending criteria for the admission of vendors to the program, recommending the minimum training required for authorizers, and recommending accountability strategies for authorizers and vendors.

In order to accomplish the objectives, the consulting firm reviewed relevant documents such as AADL policies, vendor applications, minutes of stakeholder advisory committee meetings, and the *Long Term Care Review* (Broda Report). It also conducted a focus group with AADL staff to explore issues related to the current program mandate, develop principles and criteria for adding/removing products, and discuss implications associated with changing the AADL program mandate. Additionally, 180 selected stakeholders were interviewed, including 72 authorizers, 61 vendors, 16 RHA representatives, five AADL clients, 14 AADL staff, three other provinces

and nine client advocacy groups. A final focus group with AADL staff was then held to discuss the results from the stakeholder interviews, and to develop recommendations to guide the AADL program in the future.

In the sidebar are some of the 19 recommendations that would have a direct impact on AADL clients.

For more information on the Mandate Review, please contact Alberta Aids to Daily Living at 780/427-0731 (toll-free through the RITE operator from anywhere in Alberta—call 310-0000) or your local Regional Health Authority (RHA).

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AADL Review: Key Recommendations

Recommendation #1

That AADL expand its program mandate in two areas. First, address the "short-term" need for products and equipment in response to the early discharge of individuals from hospitals. Second, expand its mandate to provide the necessary products and equipment to assist people in achieving as much independence as possible in their home or home-like setting, rather than simply meeting clients' basic needs.

Recommendation #4

That AADL annually review the "quantity and frequency limits" associated with providing equipment, in order to determine if its current policies are effective in responding to a client's changing needs in relation to the progression of his/her condition.

Recommendation #11

That AADL develop a Complaints Registry to document who complains, the nature of the complaint, who was designated to investigate the complaint, findings of the inquiry, and action taken.

Recommendation #15

That AADL randomly check with clients to ensure authorizers are providing clients with a choice of potential vendors.

Recommendation #17

That AADL investigate elimination of the requirement for clients to share in the cost of program benefits.

Recommendation #19

That AADL re-design its Benefit Appeal Process.

Municipal Funding for Accessibility

Municipalities seeking funding for accessibility projects need look no further than the Alberta's Unconditional Municipal Grant Program (UMGP).

Through the Ministry of Municipal Affairs, this annual provincial grant is allocated to some of the 319 municipalities.

Municipalities that are eligible must have been incorporated prior to 1993. The annual grant is based on an amount of \$3.19 per capita. The UMGP uses the 1993 census for its calculation of the grant and provides additional funding to municipalities that have a current and formalized transit system or that have identified themselves as piloting a formal transit service.

The purpose of the UMGP is to assist municipalities with local expenditures for parks, public transportation, police assistance, and transportation and

building accessibility. For information on the whether or not your municipality receives the UMGP—or how much it receives—please refer to your municipal profile by accessing the Ministry of Municipal Affairs website at www.gov.ab.ca/ma/cfm/profiles/index.cfm.

In spring 2001, the Premier's Council Secretariat undertook a research project to review the municipal profiles and to determine which municipalities are using the UMGP to fund accessibility initiatives in their communities. From the Council's research on the UMGP, there appears to be no formula for how the grant is allocated in the four areas or for a minimum amount that each area must receive per year.

Once the UMGP is forwarded to the eligible municipality, the money is put in general revenue and then it is up to the munici-

pality's officials to decide how the money will be used in the community. Further research on the grant illustrated that few municipal officials were aware of the UMGP and that there is no reporting mechanism in place to account for how the UMGP is being used in communities.

Given the absence of a reporting requirement and a lack of awareness of UMGP, the Secretariat saw an opportunity to inform Albertans about the funding by creating an education package for municipal officials and interested disability stakeholders. This package will consist of information about the UMGP, eligibility requirements, application process, and Accessibility Guidelines for building and transportation. The Council anticipates the package will serve citizens by providing them with the necessary information to request funding

from municipalities for accessibility projects in their respective communities.

Since the UMGP covers funding for four areas, it appears that the areas that get the funding are the ones that receive the most attention by the municipality. It's difficult for accessibility initiatives to compete for funding with parks, public transportation, and police assistance.

The UMGP isn't the answer to all of the funding required for making Alberta's communities accessible, but it is funding that disability stakeholders need to be aware of and to consider in their advocacy for inclusive communities. The Secretariat anticipates that the education package will be available for distribution in late summer 2001. For more information about this project please contact Sherri Tanchak at 800/272-8841 (voice or TTY).

Champions Unite!

Champions Career Centre, located in Calgary, is Canada's first cross-disability employment and resource centre involving a tri-sector partnership. The Alberta Government, the disability community and corporate Alberta have all come together to increase the workforce participation rates of persons with disabilities. They do this by providing disability services, funding the Centre, and hiring job candidates at Champions.

Since opening in October 2000, Champions Career Centre has been successful in drawing extensive community support. On June 28, the Champions Shareholders' Meeting celebrated the membership signing of twelve organizations, partner-

ship agreements with ten more and continued discussions with nine prospective service providers (see photo). These partnerships, combined with the support of private allies such as TransAlta, Royal Bank Financial Group, Ogilvy & Mather, SMED International, along with Alberta Hu-

man Resources and Employment, make this one of the largest collaborative initiatives aimed at improving the employment status of persons with disabilities.

"We're getting some great support from community agencies, and from Corporate Alberta," says John Petryshen, director of operations at Champions. "We're seeing more clients, the resource centre is being utilized, community agencies are

using the training room for workshops, and on a majority of days all computers are utilized by clients, doing their job searches, which is a very positive thing."

Champions has made approximately 50 job and education placements in recent months and anticipates greater numbers as word of the Centre spreads. For more information about Champions, call the Centre at 403/265-5374.



Filling the Information Gap

An Albertan dedicates herself to providing answers for autism

Karen Leigh Simmons knows how to channel her frustration into innovation.

A resident of the Edmonton area since 1984, Simmons has had her share of frustration searching for information about and resources dedicated to autism.

"It all began in 1994 after my fourth child, Jonny, was diagnosed with autism," explains Simmons. "To make a long story short, I decided to write a book to help my son and others like him understand what is commonly known as 'the invisible disability'. *Little Rainman*, written through Jonathan's eyes, has been sort of an 'operations manual' to help teachers, siblings, peers and even Jonny along the way of his autism path by helping them recognize the early warning signs of autism. Published six months after completion, *Little Rainman* has sold over

10,000 copies worldwide."

Lack of access to information also led Simmons to launch Exceptional Resources, Inc. (www.exceptionalresources.com), which is dedicated to make autism-related books, videos and other materials more readily available to parents and professionals.

Success with that company and her book convinced Simmons to develop yet another autism information resource—an interactive online autism newsmagazine and community called *Autism Today* (www.autismtoday.com), which was officially launched this past May. This online magazine offers a wealth of information and resources for people with autism and their families—articles from leading experts in the field such as Dr. Temple Grandin and psychologist Nathan Ory; stories, poems, music and art from people with autism, their family and their friends; a public discussion forum where readers can share stories, ideas and talk; polls and surveys where readers can voice their opinion; and links to a variety of autism-related resources and sites.

Simmons' goal is to develop a grassroots online community, resource centre and news magazine to help people worldwide find treatment options and models, locate ongoing conferences and resources, discover early intervention tools and strategies, and provide a method of targeting candidates for potential research in the autism area.

"We're working very hard to make our site the most user friendly, informative, single source for autism related information in the world," says Simmons. "We actively change the site to provide quality information and have many interactive opportunities for parents,



Karen Leigh Simmons

professionals, educators, teachers, siblings and people with autism so we can bring them back again and again. We strive for the best because that is what will bring people back. Even people with autism will have a way of expressing their unique talents and abilities while finding friends with similar interests online. There are no limits to the information sharing that will take place."

As a parent to an autistic child, Simmons knows the challenges that face families with newly diagnosed children. It's these families, she says, that can most benefit from *Autism Today*.

"The problem is that this is such a debilitating disability, which more often than not consumes most, if not all, of the parents' time and money," she explains. "If parents are fortunate enough to first recognize the warning signs, then get past their denial of the possibility of autism diagnosis, and on top of that, get past the waiting list—which can be up to two years in some areas—and finally get the child into an early intervention program before the age

of five, then their chances of a better outcome increase ten fold."

Simmons stresses that great pains have been taken to make the *Autism Today* interactive, and she urges people to get involved.

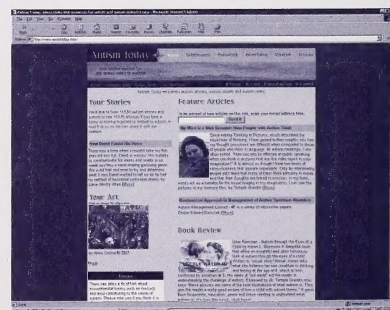
"Every parent, sibling and even teacher has a heart-warming story to tell about the child in their life with autism. We have a place online for anyone to submit these stories along with their permission for us to use their story. We have polls, contests and fun interactive tools for everyone. Another area of contribution that will make all the difference in the world is that potential authors may have their work published online, eliminating most costs associated with the publishing process such as printing costs, acceptance from publishers, expensive agents and so on. What better way to find the unique talent, heart-warming stories and unique strategies experienced people have to offer that would not be available in any other format? From first hand accountings to successful treatment techniques, we cannot think of a better way to educate the world."

Currently, Simmons is organizing a downloadable online toolkit for parents and educators to use. It will initially include social stories, a guide to facial expressions, behavioral strategies and communication ideas. "We invite people to submit their material right away for any consideration along with any comments to info@autismtoday.com," she says.

For more information, visit www.autismtoday.com or call toll-free 1-877-482-1555 (482-1555 in Edmonton).

Facts About Autism

- Autism has only been recognized since 1943.
- Cause remains unknown, and doctors can offer no proof that a child has autism—they make the diagnosis by comparing a child's behaviors and abilities with others that have the disorder.
- Autism occurs in about one out of every 2,000 births and, in almost every case, it is a lifelong condition. Those with autism are often also developmentally disabled.
- As an estimated 50% of people with autism are non-verbal. Along with the difficulty of communication comes major behavioural challenges such as tantrums, head-banging, biting and other forms of aggression.
- People with autism are usually appear outwardly normal, which has led to it being known as the "invisible disability".



WavePOINT to Carry Out Randomized Controlled Trial

WavePOINT Systems Inc., the Edmonton-based company that has a developed a non-invasive, non-pharmaceutical method of treating attention deficit/hyperactivity disorder (ADHD), recently announced plans for a randomized controlled trial.

The trial will compare the effectiveness of the *WavePOINT* Program for ADHD to the current pharmaceutical standard of treatment, the drug methylphenidate (marketed under such brand names as Ritalin and Concerta). The design phase, intended to be completed by September 30, 2001, will determine the size, scope, timing, and cost of the trial.

"Demand for a proven alternative to methylphenidate is an increasing trend among patients, health care workers, and others involved in treating ADHD," says Jason Randhawa, *WavePOINT*'s President and CEO.

"A vast amount of clinical and



WavePOINT Systems is seeking conclusive proof that it can help young people with ADHD

published evidence surrounding the type of intervention being offered by *WavePOINT* already exists. Demonstrating effectiveness via a randomized controlled trial will affirm this, and what *WavePOINT* has already shown via results with over 400 patients to date—that we have an effective, non-invasive intervention for ADHD.

The company's hope is that, by confirming the success of its technology, it will be able to offer the treatment on a wider scale and take advantage of significant reimbursement opportunities

via health care funders such as government, insurance companies, and HMO's in the process.

The company also recently announced the appointment of Dr. Terry Klassen to the company's Scientific Advisory Board. Dr. Klassen is currently Chair of the Department of Pediatrics, University of Alberta and Clinical Leader for the Child Health Program, Capital Health Authority in Edmonton, Alberta, Canada.

"*WavePOINT* is extremely excited about the addition of Dr. Klassen to our Scientific Advisory Board," says Randhawa. "His

background in child health and experience in randomized trial design will become extremely helpful as the company prepares to initiate several strategic initiatives shortly."

ADHD is the most common neurobehavioral disorder affecting school-aged children. A significant number of adults are also affected. Symptoms include inattention, impulsiveness, and hyperactivity. Result difficulties can include problems with schoolwork, strained interpersonal relationships, under-employment, and low self-esteem. The disorder can be characterized physiologically by difference in brain function, demonstrated by an increased level of slow (theta) brain wave activity when trying to focus and concentrate on a school-type task.

The *WavePOINT* Program represents a comprehensive approach to treating ADHD that includes assessment, counselling, and direct interaction with the client's family, school and health care providers. An alternative to traditional pharmaceutical based interventions, the program incorporates proprietary neurofeedback protocols and training to teach individuals to change the way their brain functions, resulting in an increased ability to focus and concentrate. The client, whose brain wave activity is monitored via EEG (electroencephalogram), receives real-time visual and auditory feedback of how their brain is functioning. Over the course of 40 training sessions, the client acquires a cognitive skill, which enables them to focus and concentrate in a variety of real life situations—for example, during school, work, sports. According to *WavePOINT*, the program reduces or eliminates the need to use medication to mitigate symptoms and results in a significant, measurable improvement in the abilities of clients to attend, focus, and regulate behaviour post-training.

For more information, contact *WavePOINT* at 780/451-5233 or visit www.wavepointsystems.com on the Internet.

New Software Allows Visually Impaired Better Internet Access

GW Micro, a Fort Wayne, Indiana-based adaptive software company, recently released Window-Eyes 4.1. The company describes the new version as "the most flexible, configurable, and responsive software for people who are blind allowing them to both listen to and feel all the wonders available through personal computers."

The update includes support for Grade 2 Braille and 30 Braille displays. It also provides enhanced support for Internet applications such as Internet Explorer 5.5, the soon to be released Internet Explorer 6.0, Outlook Express 5.5, Outlook 2000, Eudora, PMMail, Agent, and much more.

Window-Eyes 4.1 offers a user-friendly interface utilizing standard Windows controls like check boxes, list boxes, and buttons. Changing settings

such as Braille displays, synthesizers, volumes, pitches, tones, rates, verbosity settings, mouse control, and keyboard control are all done with a few keystrokes. These changes can be saved in set files and passed around from user to user.

Users have the ability to toggle between Grade One and Grade Two Braille.

GW Micro has also collaborated with Adobe Systems in creating Adobe Acrobat 5.0 and enhancing their respective products to allow people who are blind to read PDF documents. It's as though they are viewing a web page, and it's easy to fill out complicated electronic forms. The result, say both companies, is that the majority of PDF documents that were once inaccessible are now available for all.

Concern Grows Over Arthritis

Around the globe, concern is growing about arthritis and its reputation as the leading cause of disability in adults.

In April, the U.S. Centers for Disease Control and Prevention released a bulletin entitled *Arthritis: The Nation's Leading Cause of Disability*.

In the bulletin, which is based on data collected in 1999, the authors claim that arthritis and other rheumatic conditions (including osteoarthritis, rheumatoid arthritis, fibromyalgia, lupus, childhood arthritis, gout, bursitis, Lyme arthritis, and carpal tunnel syndrome) affect nearly 43 million Americans, or about one of every six people, making it one of the most prevalent diseases in the United States.

"These diseases and conditions can drastically reduce a person's quality of life," write the authors. "Arthritis is the leading cause of disability in the United States, limiting everyday activities for more than seven million Americans. In many cases, arthritis deprives people of their independence and disrupts the lives of family members and other caregivers. In addition, disabilities from arthritis create enormous costs for individuals, their families, and the nation. Each year, arthritis results in 44 million outpatient visits, almost three-quarters of a million hospitalizations, estimated medical care costs of \$15 billion, and estimated total costs (medical care and lost productivity) of almost \$65 billion."

If that's not enough, the authors say that the impact of arthritis is expected to increase dramatically as baby boomers age: "By 2020, an estimated 60 million Americans, or almost 20% of the population, will be affected by arthritis, and nearly 12 million will experience activity limitations."

The bulletin also attempted to dispel the myth that arthritis is a senior's disease. "In actuality, arthritis affects people of all ages, and half of people older than 65 years do not have arthritis," write the authors.

They add that some types of arthritis can be prevented—for example, weight control and injury prevention measures can lower a person's risk for developing osteoarthritis. And for people who do develop arthritis, the accompanying pain and disability can be minimized through early diagnosis and appropriate management, including weight control, physical activity, and programs to increase people's ability to manage their condition. However, the authors expressed concern that such programs are rarely recommended by physicians, who might not know about the effectiveness of these interventions or doubt that their patients will comply.

Here in Canada, the Arthritis

Society (TAS) and the Canadian Orthopaedic Association (COA) have been sounding their own alarm bells. In June, the two organizations jointly kicked off a campaign to improve access to orthopaedic care for people with arthritis—and to raise awareness of the fact that more than four million Canadians have bone and joint-related health problems which have a tremendous human and financial impact.

In a June 11 joint news release, the two organizations point to a new study by the Institute of Health Economics which estimates the indirect economic impact of bone and joint problems—including arthritis—totalled \$17.9 billion in 1997, the most recent year for which complete data were available. The biggest reason for this staggering number, say TAS and COS, is the result of lost productivity of people who are unable to work and conduct business. As the population grows

and ages, these costs are expected to rise dramatically.

The economic study also reveals that osteoarthritis is two and a half times more prevalent in Canada than heart disease, and over six times more prevalent than cancer. Because of demographic trends, it's estimated that in the next 30 years, the number of people with bone and joint-related health problems in Canada will increase by 124 per cent.

Meanwhile, a parallel survey conducted by Decima Research revealed that 42% of Canadians have been affected by bone and joint problems—either personally or through the severe physical pain of a family member or friend—and 59% of Canadians want governments to spend more to address orthopaedic and arthritis-related health problems such as hip and knee replacement surgery.

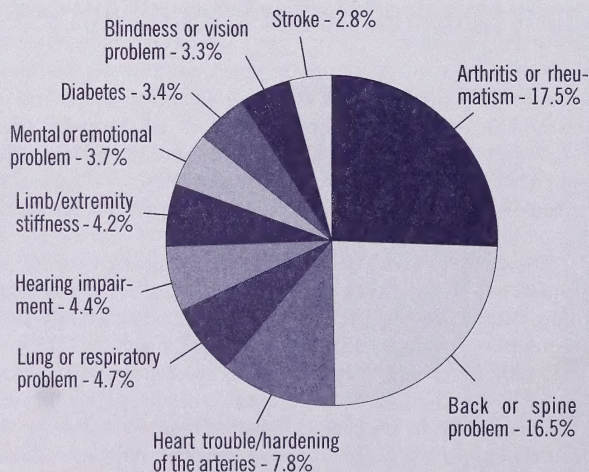
"Orthopaedic care is one of the first and greatest Canadian health care challenges of the 21st century," says Dr. Cecil Rorabeck, president of the Canadian Orthopaedic Association. "These studies show that access to care is in serious jeopardy—and the problem is reaching crisis proportions. That's why Canadians expect action from governments and the medical community."

But despite surging demand, say the two organizations, a severe shortage of orthopaedic surgeons makes it difficult for people to get the care they need. On average, patients are forced to wait more than six months for joint replacement surgery in Canada, and many have to wait a year or longer. For the estimated 20,000 Canadians waiting for hip or knee replacement surgery, life is often wrought with severe physical pain, emotional and financial problems. Four out of five Canadians say orthopaedic problems have a severe impact on the mobility of the patient and their ability to perform daily activities that most of us take for granted.

"The critical lack of access to orthopaedic care is making life very

The Most Frequent Causes of Disability Among Americans Aged 18 Years or Older, 1999

Source: CDC. Prevalence of disabilities and associated health conditions among adults—United States, 1999.



difficult for thousands of Canadians," says Barbara Stokes, Director of Client Services, The Arthritis Society, Eastern Ontario Region. "We need to start putting patients first—and that's what today's announcement is all about."

The announcement referred to by Stokes is for a plan entitled *Canada in Motion: Mobilizing Access to Orthopaedic Care*. It proposes developing national standards for waiting times; establishing methods to improve access to care and treatment in underserved and rural areas of the country; expanding outpatient treatments and services; recruiting and retaining the surgeons Canada needs; and enhancing the quality of patient care through improved coordina-

tion, education and information for patients and health professionals alike.

"We've developed this comprehensive plan to ensure Canadians have timely access to orthopaedic procedures like joint replacements—when and where they need them," says Stokes.

TAS and COA aim to present their plan to governments across the country to put orthopaedic care on the public agenda and improve both access and quality of care.

Both organizations recognize Alberta as a leader in addressing the problems—our government has pledged \$125 million to create a Bone and Joint Centre of Excellence that will open in Calgary in 2005. However, TAS and COA say that, while this cen-

tre will help to address access to orthopaedic care in the long term, there are still critical shortages of orthopaedic surgeons, operating room time, hospital beds and other equipment needed to deliver timely access to joint replacement surgery. As a result, TAS and COA are urging Alberta to join them in a call for a national strategy on orthopaedic care.

"Orthopaedic care is one of the first and greatest Canadian health care challenges of the 21st century," says Dr. Gerry Kiefer, President of the Alberta Orthopaedic Society. "These studies show that access to care is in serious jeopardy across the country. Alberta has taken great strides to address patients' long-term needs, but the job is not

yet done. That's why we want to continue to address this problem in partnership with federal and provincial governments, as well as the health community."

The Canadian Orthopaedic Association is the organization that represents Canada's orthopaedic surgeons. The COA is committed to delivering the highest quality of patient care by providing timely access and sufficient resources to treatment such as hip and knee replacements. The Arthritis Society is Canada's only not-for-profit organization dedicated to funding and promoting arthritis research and care. Since its inception in 1948 it has contributed more than \$100 million toward arthritis research.

Disabled Golfer Wins Right to Use Cart On Tour

In a clear 7-2 decision, the Supreme Court of the United States ruled in June that professional golfer Casey Martin can use a golf cart during PGA Tour events.

The court decided that under the Americans with Disabilities Act (ADA), the PGA Tour had to waive its requirement that golfers must walk the course while competing in tournaments.

"Under the ADA's basic requirement that the need of a disabled person be evaluated on an individual basis, we have no doubt that allowing Martin to use a cart would not fundamentally alter the nature of PGA Tour tournaments," wrote Justice John Paul Stevens in the majority opinion.

Lawyers for the PGA Tour argued that walking in between holes contributed to a fatigue and that allowing Martin to drive would give him an unfair advantage. The majority of justices didn't see it that way, ruling the walking requirement "is at best peripheral to the nature of the (PGA Tour's) athletic events, and thus it might be waived in individual cases without working a fundamental alteration."

Stevens also acknowledged that Martin's rare circulatory disorder called Klippel-Trenaunay-Weber syndrome results in more fatigue than walking due to intense pain.

Martin, who has been playing on the Buy.com tour using a cart, learned of the decision from PGA Tour Commissioner Tim Finchem, who called Martin to congratulate him.

"My reaction was relief," said Martin during a media conference call. "It was a great feeling...I think this opens the door for people. I think, before an institution like the PGA Tour or other sports groups, before they automatically knock down somebody's desire for accommodations, they might have to think twice and hopefully give some careful consideration. So it might cause some people to think, those

that are in those decision-making positions and hopefully it will have a trickle down effect."

The two dissenting votes came from Justices Antonin Scalia and Clarence Thomas. "In my view today's opinion exercises a benevolent compassion that the law does not place it within our power to impose," wrote Scalia. "The judgment distorts the text of Title III, the structure of the ADA, and common sense."

In a prepared statement, Commissioner Finchem said that the tour would now "fully review and evaluate the Court's decision, and how that decision and the applicable requirements of the ADA might affect the Tour's regulations and rules of competition...as we have said from the beginning of this issue, the Tour has the highest respect and admiration for Casey Martin, as and

individual and as a competitor. We have believed from the beginning of this situation, however, that the issues involved go well beyond considerations involving an individual player."

Martin's case has been in the courts for more than three years. He initially sued the PGA to relax its walking rule for him in November 1997, seeking "reasonable accommodation" under the ADA. Several lower courts and the U.S. 9th Court of Appeals ruled in Martin's favour, but the PGA Tour contested the ruling each time, which ultimately resulted in the latest Supreme Court battle.

During the lengthy legal struggle, the PGA Tour allowed Martin to ride in a golf cart during competitions. He missed getting his PGA card by one stroke during qualifying competition last December, and has enjoyed only limited success on the Buy.com tour (he failed to make the cut at the first tournament after the decision, the Greater Cleveland Open). He says that now that the legal battle is over, he hopes to be able to concentrate more on his game.



Access at the Games

People with disabilities naturally want to be able to view the world's most prolific track and field stars in action. Here's what they can expect if they plan to visit the Edmonton 2001 Track and Field Championships, held August 3rd to 12th.

Commonwealth Stadium (Championships Events Venue)

- 64 wheelchair accessible seats with attendant seating
- Most new wheelchair seating is on a platform that provides an obstructed view
- Additional seating on concourse level reserved for people who cannot manage stairs but can sit in "regular" seats
- New accessible washrooms in Concourse Expansions
- Lowered height concessions in Concourse Expansions
- FM audio system for hard of hearing people
- Opening and Closing Ceremonies Speeches and Team In-

formation will be printed in both official languages on Stadium Display

Gates 6 (NW corner) and 9 (NE corner) are designated as entrances for people with disabilities—slopes are not to Code, so Volunteer Spectator Assistants will be available to help people enter, exit and move around the Stadium

At the time of writing, the Game's Disability Access Committee was still working to solve issues such as obstructed views and provision of large-print and Braille programs. Committee members will be available during the event to help deal with issues that arise.

World's Plaza (Churchill Square)

Good wheelchair accessibility, high contrast signage

Festival of the World's (Kinsmen Park)

Good wheelchair accessibility has been promised

Getting There

The organizing committee recommends that people use public transit or Park 'n Ride to get to and from Commonwealth Stadium and the Festival of the World's at Kinsmen Park. Please note that there is absolutely no parking onsite at either location. Public transit is also free to holders of same-day event tickets and Championships Accreditation.

Park 'n Ride

Edmonton Transit will be running Park 'n Ride for both the Commonwealth Stadium and Kinsmen Park venues. The Park 'n Ride Service from the Davies Lot (61 Avenue and 81 Street) will have exclusively Low Floor Bus service, but all locations will have some Low Floor Bus service. Details at 496-1611 or www.takeETS.com

Strathcona Transit will operate a Park 'n Ride service to the Opening and Closing Ceremonies, Aug 3 & 12. Details at 464-7433.

At Commonwealth Stadium, a designated Drop Zone for DATS and other accessible vehicles will be set up at 111 Avenue & 90 Street, at the NW corner of Sta-

dium. Private vehicles must display a valid disabled parking placard for access to that zone.

Disability Events

Sunday Aug 5

Men's 200m Amputee
Women's 100m Amputee

Monday Aug 6

Men's 100m Blind
Women's 200m Blind

Friday Aug 10

Men's 1500m Wheelchair
Women's 800m Wheelchair

Other Venues

Other venues, such as Clarke Stadium, Rollie Miles, Foote Field, Universiade Pavilion (Butterdome), Hotel Team Village and the University Team Village are accredited zones and are not public venues, although they have been reviewed for accessibility for competing athletes and others.

More Information

The E2001 website has information with respect to accessibility features in the FAQ section (and more will be added, as information becomes available). Website is www.2001.edmonton.com.



Less Than Perfect?

While E2001 organizers say they have incorporated accessibility into all aspects of the games, not everyone's convinced. At least one disability organization, the Canadian Paraplegic Association (Alberta), is on record stating that renovations done at Commonwealth Stadium do not meet Building Code requirements. Among the cited complaints is lack of adequate wheelchair seating and poor sightlines from wheelchair seating. Organizers says the concerns have been inventoried and passed along to the City of Edmonton Commonwealth Stadium management so that improvements can be made for following the Championships.

Pain Society Publishes Patient Pain Manifesto

The Canadian Pain Society (CPS) believes that, within Canada's healthcare system, pain isn't taken seriously—despite the fact that most pain can be effectively relieved. In May, to address this concern, CPS launched an aggressive initiative—the Patient Pain Manifesto. This public awareness and education program will be aimed at alerting and educating hospital patients, and their families, regarding their rights in the management of their pain.



"The Patient Pain Manifesto was developed by the Canadian Pain Society as a 'Bill of Rights' for hospital patients and their families regarding treatment of pain resulting from surgery, treatments, or illness," says Dr. Celeste Johnston, Professor at the School of Nursing, McGill University in Montreal, and President of CPS. "Studies show that a surprising number of patients believe that suffering is part of being in hospital and being ill. We want to make sure that patients with pain are fully aware that they have the right to receive treatment that will keep their pain under control, and help them reclaim their lives."

According to CPS, one of the underlying causes of unnecessary acute pain is the lack of awareness among patients that they have the right to have their pain treated. In fact, pain can be extremely harmful; it can result in more complications, longer hospital stays, greater disability and potentially long-term pain.

Acute pain is considered easy to treat with a number of options available, which include a wide

range of drugs as well as non-pharmacological techniques. And while persistent, chronic pain can be difficult to treat, every attempt should be made to do so, says CPS.

The Patient Pain Manifesto is based on the premise that awareness and education are of primary importance. Patients need to know that pain is a medical condition that can—and should—be treated, just as infection, diabetes or high blood pressure are treatable. But, in order

for health professionals to treat pain, the patient or their family must report the type and level of pain to their caregiver. The Patient Pain Manifesto provides a tool to help them do this. Health professionals then have a responsibility to assess pain routinely, to believe the patients' pain reports and to help prevent the pain.

CPS stresses that very young children and some elderly patients may be unable to voice how much they're hurting or the nature of their pain. Correspondingly, family members and healthcare professionals need to find ways to interpret facial expressions, and other forms of non-verbal communication.

CPS is a chapter of the International Association for the Study of Pain. Based in Ottawa, members include health professionals, scientists, university educators, and corporations. Its goal is to improve the management of patients with acute or chronic pain through education and research. For more information, visit the CPS website (www.medicine.dal.ca/cps).

Need quality employees? Look to persons with disabilities, says Conference Board of Canada.

In the race for employee talent, people with disabilities represent a largely untapped source of workers, according to a new resource guide released in May by The Conference Board of Canada in partnership with the Government of Ontario's Ministry of Citizenship.

"Most employers have policies and practices in place that encourage the hiring and retention of a diverse workforce," says Ruth Wright, author of *Tapping the Talents of People with Disabilities*. "But employers told us that they needed help finding candidates with disabilities for job openings. So we produced this employers' resource based on extensive research. We developed it as a concise, user-friendly resource with examples of good practice companies."

"Diversity in the workplace offers us a significant economic advantage in Ontario," says Minister of Citizenship Cam Jackson. "This partnership represents an essential aspect of this government's commitment to finding shared solutions to address the needs of people with disabilities. Legislation alone will not achieve our goals. We need other organizations and individuals, like the Conference Board, to work in partnership with us."

According to the Conference Board of Canada, people with disabilities represent a significant group of consumers. In Ontario alone, about 1.6 million people have some form of disability—a compelling argument to hire people with disabilities and reflect their needs as customers in the process.

However, the Conference Board research found that employers need help to accommodate employees with disabilities, especially in restructuring jobs due to the nature of work, and with perceived cost-related factors. Employers reported a need to dispel myths and stereotypes about workers with disabilities, both among co-workers and within society at large.

The guide was developed from information gained through a survey of Ontario-based employers, a multi-stakeholder roundtable, interviews with organizations that have retained persons with disabilities, and seminars held across the province. It sets out practical steps an employer can take to improve the workplace representation of people with disabilities as well as recruitment strategies, including practical checklists, resources and contacts. Leading organizations such as IBM Canada, Motorola, Canadian Tire and Casino Niagara are cited as "good practice" examples.

The guide is available in English and French, as well as a variety of alternative formats including Braille, diskette, audiocassette and large print.

The Conference Board of Canada is dedicated to bringing "Canadian business, government and public sector organizations together and provide insights, which allow our members to anticipate and respond to an increasingly changing global economy."

For more information, visit the Conference Board of Canada website (www.conferenceboard.ca) or call (613) 526-3280.

Netherlands OKs Assisted Suicide

On April 10th, the Netherlands became the first nation to legalize physician-assisted suicide when the Dutch Parliament's upper house passed the bill by a vote of 46 to 28.

While the new law makes it legal for a person with an unbearable, terminal illness to ask a doctor to end his or her life, euthanasia has actually been a long-standing Dutch practice, and it's estimated that up to 3,500 people have been euthanized each year in the past decade.

Before the vote, Health Minister Els Borst reassured senators that the law could not be abused by doctors. "There are sufficient measures to eliminate those concerns," Borst told the senators, adding that euthanasia will remain a last resort for those wish to end their suffering.

The law, which will be enacted this summer, requires that patients be legal residents of the Netherlands. A patient would have to be experiencing irremediable and unbearable suffering, be aware of all other medical options and have sought a second professional opinion. The request would have to be made voluntarily, persistently and independently while the patient is of sound mind. Doctors are not to suggest it as an option. The new law also allows patients to leave a written request for euthanasia, giving doctors the right to use their discretion when patients become too physically or mentally ill to decide for themselves. An independent commission would review cases to ensure the guidelines were followed.

As the bill was passed, thousands of people protested outside the Dutch Parliament.

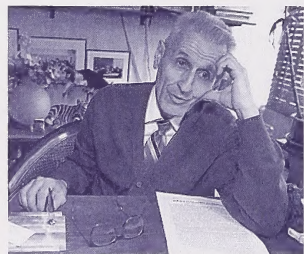
Disability and religious groups worldwide have condemned the law, while many pro-euthanasia groups have praised the Dutch model.

Switzerland, Colombia and Belgium are other countries which tolerate euthanasia. In the United States, Oregon has allowed doctor-assisted suicide for the terminally ill since 1996, but its law is more restrictive.

Meanwhile, The Canadian Press recently published results of a national poll that suggests a majority of Canadians are in favour of assisted suicide. The poll, conducted by Leger Marketing of Montreal, revealed that 75.5 per cent of Canadians believed someone who has helped end the life of a loved one suffering from an incurable and extremely painful illness should not be prosecuted.

The survey included 1,507 people.

At 84.1 per cent, people in Quebec were most opposed to prosecution. B.C. followed at 76.8 per cent, while Albertans were near the bottom of the list at 64.1 per cent.



Support for Dr. Death: public opinion polls in the U.S. have demonstrated widespread support for Dr. Jack Kevorkian (above), the retired pathologist who has helped 130 people end their lives. Kevorkian is currently in a Michigan prison pending an appeal of his 1999 murder conviction.

New Zealand Announces Disability Strategy

New Zealand has launched a strategy designed to remove the barriers which prevent its citizens with disabilities from participating fully in society.

The strategy, entitled *Making a World of Difference*, outlines 15 objectives in areas such as human rights, social attitudes, education and employment, recreation and lifestyle, information, public services and support systems.

"Societies are built in ways which assume we can all move quickly from one side of the road to the other, that we can all see signs, read directions, hear announcements, reach buttons, climb stairs, open heavy doors, interpret complex information, and have stable moods and perceptions," Prime Minister Helen Clark said in announcing the strategy. "But, for the one-in-five New Zealanders with a long-term impairment, that is not necessarily the case. Many are unable to reach their full potential or participate fully in our communities because of the barriers they face doing everyday things."

Clark says that, while the Strategy reflects government's commitment, New Zealand society and the public must also work toward removing barriers.

"This challenges all New Zealanders to ask themselves whether they judge people by what they can't do, rather than what they can do," she said.

The Minister for Disability Issues, Lianne Dalziel, described the strategy an "excellent starting point on which to build a fully inclusive society where disabled people are able to participate in our communities and reach their full potential."

Check with the New Zealand government website for more information (www.nzds.govt.nz).

IPC Removes Intellectual Disability Category

Following the wake of the Paralympic scandal involving a Spanish basketball team, the International Paralympic Committee (IPC) has suspended the International Sports Organization for Athletes with an Intellectual Disability from its membership.

Last December, it was revealed that ten members of the Spanish intellectually disabled basketball team did not have a disability and had falsified their IQ as being below 75 in order to compete. The team had captured the gold in the event, but was forced to relinquish its medals by the Spanish Paralympic Committee when the scandal erupted. The Committee subsequently launched an investigation to determine if other Paralympians in athletics, swimming and table tennis had also falsified their IQ.

The IPC's ruling is a blanket ban which prevents all athletes from participating in any IPC-sanctioned event. IPC officials have indicated they are investigating allegations of falsified eligibility with other countries' athletes, and are examining the process of determining whether or not intellectually disabled athletes qualify to compete.

Disability organizations representing people with developmental disabilities have protested the ban.

Accessible Transit: The View from My Chair

As almost everyone knows, the cities of Edmonton and Calgary are working toward making their entire fleet of buses and light rail transit cars (LRT in Edmonton, C-Train in Calgary) more accessible to people with disabilities. I hope that, in writing this brief editorial, I can relate my experiences and help encourage more folks to give accessible “regular” transit a try.

I’ve heard comments indicating an element of uncertainty and fear and a few horror stories from people with disabilities about using low-floor buses and rail transit. Certainly, not everyone will be able to take advantage of these new travel options, and DATS and HandiBus aren’t going to disappear or be replaced by them. However, those who do use accessible regular transit can take advantage of systems that provide flexibility not previously attainable.

In Edmonton, for example, DATS users are well acquainted with the pressures on that system that result in difficulty getting a ride on the day and time

desired. Anyone who uses the accessible regular transit options helps to free up DATS rides for those who really need them.

I’m a C5/6 quadriplegic who uses a power wheelchair to get around. I’ve gone from using DATS for an average of 70 to 80 trips per month to my current use of less than one ride per month. During that time, I’ve come to appreciate the independence, flexibility and predictability offered by the bus and LRT.

Here are a few of the things I’ve discovered about accessible regular transit. First, I know that if I miss a bus, another one will be along in a while. Second, I know almost to the minute when I’m going to be picked up and when I’ll reach my destination. Third, if I’m going somewhere for a short time, I can get a ride home right away; conversely, if I’m delayed or late, I’ll usually still be able to get a ride. Fourth, I know if I’m out with friends or at a show I can get a ride after 10:30 p.m. on a weeknight. Finally, another nice benefit is that, if I’m travelling with a friend, he or she doesn’t

have to pay (Edmonton and Calgary Transit policy says an attendant doesn’t pay a fare when accompanying a DATS or HandiBus registrant riding “regular” transit).

There are drawbacks and challenges to using the low-floor buses, but I believe there are solutions to most hurdles, and that the benefits far outweigh the drawbacks.

One of the biggest problems is using the buses independently. However, in my experience, most drivers and passengers are quite willing to help if asked, and recently I’ve noticed that more and more passengers know how to raise the seats and to move back to make room for wheelchair users. A nice aspect of some newer low-floor buses is that the seats don’t lock down, so someone like me (limited arm and hand function) can lift the seats themselves.

Another hurdle is weather—especially during the winter, both from a comfort and safety standpoint.

and other wheel-

chair users from getting to and from the bus stop.

And, last but not least, not all the buses and rail transit cars are accessible. Eventually they will be, but in the meantime, arming yourself with information is the best way to avoid disappointment.

Printed route schedules and drivers are good sources. In Edmonton, you can also call Transit Information (496-1611) or BusLink (496-1600), or visit the Edmonton Transit website (www.takeETS.com) to help you determine what is and what isn’t accessible, and how to reach your destination. In Calgary, call Transit Information (262-1000) or TeleRide (974-4000), or visit Calgary Transit on the Internet (www.calgarytransit.com).

Now, if only grabbing an accessible taxi was so easy. Of course, that’s another entire article, but one that I hope can be written one day from just as positive of a viewpoint!

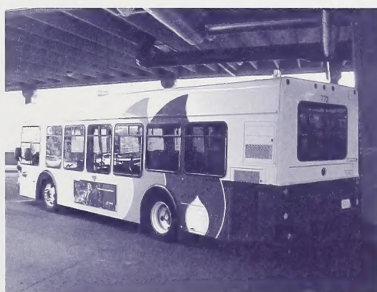
Ewen Nelson is Manager of Information Systems at the U of A’s Steadward Centre.

Medicine Hat Commits to Accessible Transportation

By 2004, Medicine Hat’s transit system will be completely wheelchair accessible with a full line of low floor buses.

The southern city, which has had its own public transportation system since 1970, is seeing a considerable growth in population. As corresponding demand for more transit increases, more low-floor people buses will be introduced.

“One of our roles is to be responsive to the transportation needs of all citizens so they can participate in a vibrant, healthy and safe community,” says Hugh English, manager Medicine Hat Transit. “I guess obvious to most is that the high floor buses came with severe restrictions for persons with disabilities. Our focus was to look into what the community’s needs were going to be, and how we could address the accessibility issue.”



One of the City’s 13 low floor buses

In 1997, an advisory committee suggested low floor buses would be ideal to help increase the ability of persons with disabilities to access regular transit. At that point, the City took arrival of its first midsize low floor buses. Since then, all new additions to the fleet have been of the low floor variety.

Medicine Hat Transit presently has 13 accessible low floor buses in the 30 to 40 foot size range and four Orions that deal mostly with special transit. Three more 40-foot low floor buses are expected to be delivered by next March.

“Our normal system is about 70 to 75 percent fully accessible now,” says English.

Low floor buses have the ability of kneeling down to the curb. They also have a power ramp for wheelchair access.

—Courtesy CPA Alberta

Book Profiles Prominent Disabled Canadians

The Canadian Abilities Foundation has launched a new book, *Making a Difference: Profiles in Abilities*, by Daryl Rock. The book profiles well-known and not-so-well-known Canadians with disabilities through inspirational stories.

Rock, who uses a wheelchair, dedicated a year to travelling across the country, seeking out extraordinary individuals, and interviewing them along with their friends and families to draw vivid pictures of the kind of person it takes to really make a difference.

"*Making a Difference* brings the reader through both time and space," says Raymond Cohen, President, Canadian Abilities Foundation. "In addition to the beautiful profiles created by Daryl Rock, several more have been extracted from the last fifteen years of *Abilities Magazine*, the national publication produced by the Canadian Abilities Foundation."

"It is interesting that such a high proportion of our Canadian heroes seem to be people with disabilities; inspirational people like Terry Fox and Rick Hansen," says Rock. "What is significant to me is that there are so many more individuals—kind of unsung heroes who, in their own ways, have overcome monumental obsta-

cles—and accomplished truly great things. I wanted to capture the highlights of the lives of some of these people within *Making a Difference* to ensure that there will be a lasting testament to their efforts and experiences."

The publication, sponsored by the Millennium Bureau of Canada, Scotiabank and Delta Hotels, is the latest of several disability-related books published by the Canadian Abilities Foundation.

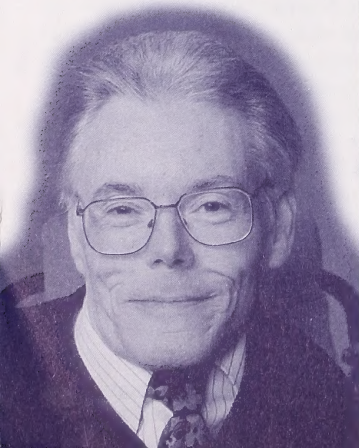
"Scotiabank supported this effort because we recognize how important it is that these stories are told and these unsung heroes are recognized," says Arlene Russell, V.P., Diversity & Employee Relations. "At Scotiabank it is a priority to be an employer of choice for a diverse workforce that includes people of all national backgrounds and abilities."

A reception was held on Parliament Hill in Ottawa on May 31 to launch *Making a Difference*. In attendance were Mrs. Aline Chrétien and Deputy Prime Minister Hon. Herb Gray, Members of Parliament, representatives from the disability community and spokespersons for the sponsors.

Rock has been active in the disability field since a car crash in 1983 resulted in his using a wheelchair. Daryl works for the federal government, from which he took a leave of absence in order to research and write *Making a Difference: Profiles in Abilities*.

To order the book, contact the Canadian Abilities Foundation at 888/700-4476. To view the book's online version, visit www.enablelink.org/MakeADif/Wel.htm.

Among those profiled in Daryl Rock's new book is Gary McPherson, former Chair of the Premier's Council.



Reeve and Researchers Sue U.S. Government

Quadruplegic actor Christopher Reeve has joined researchers from the United States and Australia who are suing the U.S. government for withholding of funding for stem cell research.

The lawsuit, filed in May, claims that the Bush administration is causing "irreparable harm" by holding up funding for stem cell research.

Many prominent scientists believe stem cells, or "mother" cells, are the key to regenerating nerve and brain cells in people who have sustained traumatic injuries. But due to an ongoing policy review ordered by President George W. Bush, the funding process for stem cell research was halted in April. In particular, Bush has indicated he is particularly concerned with research that utilizes stem cells from human embryos.

The lawsuit was initially filed by a prominent group of researchers (Dr. John Gearhart of Johns Hopkins University in Maryland, Dr. Douglas Melton of Harvard University, and Dr. Alan Osborne Trownson of Monash University in Australia) and two individuals with disabilities (James Cordy, of Pittsburgh, who has Parkinson's disease, and James Tyree, of Chicago, who has diabetes).

In a statement, Reeve said he joined the lawsuit "because of the hope that all stem cell research offers to improve the lives of millions of Americans suffering today from Alzheimer's, Parkinson's, diabetes, spinal cord injuries and other afflictions."

While Reeve and the suit's plaintiffs are in favour of the research being funded, several powerful anti-abortion groups and some ethicists are in opposition because they think it could encourage the generation of embryos purely for science.

In March, a California adoption agency sued the government for allowing the research funding. In that lawsuit, the plaintiffs, Nightlight Christian Adoptions, stated, "the process of 'harvesting' stem cells from human embryos necessarily entails the destruction of human embryos. Moreover, human embryonic stem cell research subjects human embryonic stem cells to substantial risk of harm."

That lawsuit was stayed pending the completion of the research funding policy review. The U.S. District Court judge who heard the case ordered that the government continue its policy of not funding the research until the review is completed.

Opponents of the research also point out that stem cells can be taken from a number of other sources—adults, bone marrow, umbilical cord blood and fat cells. Bush, who announced his bias towards embryonic stem cell research during the 2000 Presidential campaign, has said he prefers adult stem cell research.

